



Neuropathy Hope

Hope Through Caring and Education

A newsletter for members of the
Northern California Chapter of The Neuropathy Association (NCCNA)

August 2009
Volume 8
Issue 8

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Speaks in Concord

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www.pnhelp.org

BE AWARE & BE HEARD

The NCCNA board of directors recently adopted new policies and procedures designed to facilitate better communication and greater involvement with our members.

NCCNA board meetings will generally be open to our members for at least the first hour. Members may address any agenda item, or ask for an item to be added to the agenda. Those who cannot attend may send in written comments or questions. Because of logistical constraints, we do ask that anyone planning to attend let us know beforehand.

We will be publishing summaries of our meetings, and plans for our next meeting, on our website. We will also post a full copy of our meeting policy and instructions about whom to contact and how. Find these items at www.pnhelp.org/about_us/boardmtgs.html.

Before implementing any new policy or procedure, or any revision to policies, procedures, standing rules, bylaws or any item that substantially affects our groups or members, we will have at least a thirty day comment period. The board will tentatively approve an item, then accept and consider comments before finalizing that approval. Items for comment, as well as our existing policies, will be posted on the website at www.pnhelp.org/about_us/policies.html. Currently, these new policies and procedures are open for comment. *– Continued on page 7*

THIRD ANNUAL NEUROPATHY ACTION AWARENESS DAY HELD IN SACRAMENTO

The Third Annual Neuropathy Action Awareness Day was held on June 25 in downtown Sacramento. Over 250 neuropathy patients, family members, health care providers and others attended this free event to learn about neuropathy and to promote awareness of this disease. This was the event's first time in Sacramento. Dominick Spatafora, the president of the Neuropathy Action Foundation and the driving force behind this event, was unable to attend as his mother ended up having surgery that day. NAF board member Claudia Foutz stood in as host assisted by Kathleen Creason, NAF Advisory Board Member.

After three years, this event is really starting to come together well. The speakers were informative and interesting. Though long-term NCCNA members may have heard some of this general information before, it was often presented in new ways. For example, Dr. Jen Seda spoke on how "Good Immune Systems Go Bad in Neuropathy" by describing the body's immune system in military terms, likening different immune system components to national defense operations. Ernette Rivera of Concord described the presentation of Dr. Katz, who has spoken every year, by noting, "I was so fascinated with his presentation, I found I didn't take any notes and there was so much I would like to recall."

Michelle Vogel, who has addressed NCCNA members before at our advocacy conference, had her usual excellent information about understanding health insurance. She says to always read every



Stan Pashote staffs the NCCNA table. In addition to offering information on neuropathy and the organization, we had a computer playing a continuous loop of our new public service announcements.



Dr. Jen Seda

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Affiliate News

Listed below is information about upcoming meetings and where to learn more.

2009 NCCNA Board of Directors

Bev Anderson
President

Laura Niznik
Vice President

Penni L. Smith
Treasurer-Secretary
Technology Director

Amy Considine
Administrative Director

Michael Green
Director

Sandra Vinson
Director Emeritus

Dick Ward
Director Emeritus

Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.

Newsletter Design by

 Diane Blakley
Designs

Alturas

Judy Briener
For current information
(530) 233-4733

Auburn

1st Monday, 1:30 PM
Woodside Village MH Park
12155 Luther Rd.
Charlene Amos (530) 823-1504
Sharlene McCord (530) 878-8392

No meeting in August

Berkeley

3rd Monday, 6-8 PM
1st Month of each quarter
Lutheran Church of the Cross
1744 University Ave.
Alan Dampsey (510) 527-3568
adampsy@comcast.net

Brentwood (Coming Soon)
Bev Anderson (877) 622-6298

Castro Valley (Forming)

2:30 PM, Aug. 19
Castro Valley Room
Eden Medical Center
20103 Lake Chabot Rd.
Bev Anderson (877) 622-6298

Clearlake (Forming)

Barbara Dryden (707) 994-2202

Colusa (Forming)

1st Presbyterian Church
326 Jay Street
Betty Yarwood (530) 458-2908

Concord

3rd Tuesday, 1:30 PM
First Christian Church
3039 Willow Pass Rd.
Ernette Rivera (925) 689-2464

Crescent City (Forming)

Sutter Coast Hospital
800 E. Washington Blvd.
Judy Wolfe (707) 464-3008

Davis

2nd Wednesday 2 PM
Institute for Restorative Health
1460 Drew Ave.
Mary Sprifke (530) 756-5102

No meeting in August

Elk Grove

2nd Tuesday, 2 PM
Elk Grove Senior Center
8830 Sharkey Ave.
Michael Colozzi (916) 421-8103

Eureka

3rd Wednesday, 10 AM
Humboldt Senior Resource Ctr.
1910 California Street
(707) 268-8937

Folsom

1st Thursday, 1 p.m.
Journey Church
450 Blue Ravine Rd., K-2
Lorraine (916) 983-4023
Beverly (916) 984-4302

Fort Bragg (Forming)

Call for time & location
Mildred (707) 964-3030

Fresno

3rd Tuesday, 11:15 AM
Carrows Restaurant
1484 E. Shaw Ave.
Maria Chavez (559) 437-9787

Grass Valley

2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church St.
Sally (530) 268-1017

No meeting in August

Hayward (Forming)

10 AM, Thursday, Aug. 20
Denny's Restaurant
30163 Industrial Pkwy. Southwest
Bev Anderson (877) 622-6298

Jackson

3rd Tues., 10 AM-odd numbered months
Amador County Senior Center
229 New York Ranch Rd.
Laurie, (209) 223-0442
Darlene, (209) 296-1760

Lakeport (Forming)

Roberta Millard (209) 263-6891

Lincoln

3rd Wednesday, 1 PM
Raley's Event Center
765 S. Hwy 65
Diana Borg (916) 408-7017

No meeting in August

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
E. Lorene Stack (925) 447-6158

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeister Center across
the street from the church)
Susan Baldasano (209) 617-6283

Modesto

3rd Monday, 10:30 AM
Memorial Medical Ctr. Bldg
McHenry Village
1700 McHenry Ave., Ste 60B
Noreen Jones (209) 846-0954

Monterey

3rd Wednesday, 10:30 AM
odd numbered months
First Presbyterian Church
501 El Dorado St.
Don & Ann Trout (831) 372-6959

Napa

1st Thursday, 2 PM
Napa Senior Center
1500 Jefferson St.
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Oakland

1st Thursday, 1 PM
Grand Ave. 7th Adventist Church
278 Grand Ave.
Kathleen Nagel (510) 653-8625

Placerville

4th Wednesday, 1 PM
Placerville Senior Center
937 Spring St.
Frank Ruscoe (530) 647-0777

Redding

2nd Wednesday, 1:30 PM
Neighborhood Church of Redding
777 Loma Vista
Bill Morehouse (530) 221-3082
Carol Reeves (530) 549-4351

Reno, NV

2nd Tuesday, 6:30 PM
Fire Station #11
7105 Mae Anne Ave.
Gail Gutendorf (775) 626-1434

Roseville

2nd Tuesday, 7 PM
Sierra Point Sr. Res.
5161 Foothills Blvd.
Mary Lou Ward, (916) 772-5598

No meeting in August

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Anne Fletcher, (916) 391-3317
Myke Taylor (916) 487-2903

No meeting in July

San Francisco

Call to be sure of meeting day & time.
UC-San Francisco Med Ctr.
400 Parnassus Ave.
Amb. Care Ctr. 8th Fl., Rm A888
Rowena Mah, RN (415) 502-5064
Rowena.mah@ucsf.edu

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital,
2105 Forest Ave.
SJ DePaul Conf. Rm.
Stan Pashote (510) 490-4456

San Leandro (Forming)

10 AM, Wednesday, Aug. 19
First Presbyterian Church
180 Estudillo Ave.
Bev Anderson (877) 622-6298

San Mateo

3rd Thursday, 1 PM
St. Andrews Lutheran Church
1501 S. El Camino Real
Bev Anderson (877) 622-6298 (toll free)

No meeting in August

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Ave.
Barbara Webb (415) 453-9678

Santa Cruz

3rd Wednesday, 1 PM
Trinity Presbyterian Church
420 Melrose Ave.
Mary Ann Leer (831) 477-1239
maleer@comcast.net

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Santa Rosa

1st Thursday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Rd.
Willie Quarante (707) 544-3236

Sonoma

1st Friday, 10:30 a.m.
Vintage House
264 1st Street
Joann Bertolucci (707) 996-8336

Sonora

4th Monday, 2 PM
Sonora Regional Medical Center
Conference Room
L.D. Wright (209) 533-2887

No meeting in August

Stockton

3rd Tuesday, 4 p.m.
Service First of Northern California
102 W. Bianchi Rd.
Bev Mallette (209) 944-7815

No meeting in August

Susanville (To be announced)

Susan Ellen (530) 257-3864

Truckee

April thru October, 2nd Tuesday, 1 PM
Truckee Pines Apartments
10100 Estates Dr.
Bev Anderson (877) 622-6298

Turlock

2nd Wednesday, 10 AM
Covenant Village Adm. Bldg.
2125 N. Olive St.
Dee Muhlenbruch (209) 667-0042

Ukiah

Call for schedule
Bev Anderson (877) 622-6298

No meeting in August

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse,
Las Trampas Room, Walnut Creek
Nancy Ostrander (925) 930-9524

West Sacramento

3rd Tuesday, 2 PM
West Sac Fire Station #45
Community Room
2040 Lake Washington Blvd.
Sandra Vinson (916) 372-6093
slivins11@charter.net

No meeting in August

Woodland

1st Monday, 3:30 PM
Woodland Comm. & Senior Center
2001 East St.
Delia Genera (530) 661-3238

No meeting in August

Yuba City-Marysville

St. Andrew Presbyterian Church
1390 Franklin Rd.
Ken Lux (530) 673-3479

Yreka

2nd Thursday, 2 PM – Odd numbered months
Meadowlark Assisted Living Center
Terry Rees (530) 842-1577
Gene Arnold (530) 842-7744

President's Message

By Bev Anderson



An opportunity to double your investment

You recently received an invitation to make a mid-year contribution to NCCNA. Origin Biomed, maker of Neuragen, is matching contributions up to a total of \$5,000. I hope you take this seriously. Any amount contributed will double in value and will be of great help to your organization and for research to find a cure for neuropathy. Every amount we receive is spent carefully. It does take more than the dues to make appropriate progress in fulfilling our mission to provide support, information, and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research. At the end of the year, we will be sending a research contribution to The Neuropathy Association to help fund one of the research projects they award. What we receive as a result of the request for donations will make a positive difference in what is sent. This is our first opportunity to have a company matching all contributions to NCCNA in a specific time period so let's make the most of it.

Strategic Planning Day – September 26

The Board of Directors adopted a three year Strategic Plan for 2007, 2008, and 2009 based on input from a group leaders meeting and a questionnaire sent to all members. The Strategic Plan is available on our website, www.pnhelp.org. This information helped direct the design of the plan and the emphases that have been made in the years since.

It is time to design the Strategic Plan for 2010-2012. This time, we will send out a questionnaire to get input from members so members in every group can respond. This will be followed by a Strategic Planning Day on September 26, 10 AM-3 PM. All members are invited, especially those in group leadership. The location is not yet certain, but it will be in the greater Sacramento area convenient to freeways. If you would like to participate in this kind of planning, please put September 26 on your calendar now.

The day will feature general sessions, breakouts to brainstorm specific topics, and the choosing of a drafting committee to put the plan together. The final decision rests with the Board of Directors, as they will be responsible for working with the plan for the next three years. They are, however, committed to adopting it as it is presented as much as is financially, legally and logistically possible. We highly value having the ideas and knowledge out of the wide experience and capability of our members. We even hope that one or more participants will decide to become Board members.

Bev

Help With Health Care Challenges

If number not in your area, call the one listed and ask for the right number.

HICAP Health Insurance Counseling

for seniors and people with disabilities. Call Seniors First /SeniorLink at 1-800-878-9222 to make an appointment.

•••

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage. Tollfree (888) 354-4474 or TDD (916) 551-2180. In Sacramento, (916) 551-2100. www.hrh.org.

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HMO Help Center

Assistance 24 hours a day, seven days a week. (888) HMO-2219 or (877) 688-9891 (TDD).

•••

DRA's Health Access Project

Free publications about the health care and insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

HELP WANTED

Here are current needs for help. If you or someone you know could assist with any of these, please call us toll free at (877) 622-6298.

Data Entry Assistance

We need help entering some data into our new software, an easy-to-use web application. This can be done from your home.

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Board Members

Special needs are in group development, grants, public relations, and knowledge of nonprofit organization development.

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PAY ATTENTION TO YOU



(Notes from Mims Cushing's presentation at the Neuropathy Action Awareness Day, June 25, 2009, Sacramento. Mims Cushing is the author

*of **You Can Cope With Peripheral Neuropathy: 365 Tips For Living A Full Life.** www.mimscushing.org)*

1. Be excited about life – Have an awareness of what is going on that is positive.
2. Think gratitude, not attitude. Keep a “grateful journal” and list things for which you are grateful. Notice the little things that make life special.
3. Be open to new ideas.
4. Banish toxic people. “Don’t let them rent space in your brain.” You may not be able to disassociate with them completely, but keep them at a mental,

if not physical, distance.

5. Volunteer. You help yourself by helping others.
6. Love cabbages and caviar equally. Value your chores as much as your passions. It takes all you do to make your life.
7. Be kind to your body. You are not yourself if you overdo and over exert yourself. Find the right exercise for you, something you like, and do it regularly. It should not produce pain. Stop when it does.
8. Let the good times roll in. Sometimes you need to deal with impediments to letting this happen. Find a shoulder to cry and then laugh on, vent on paper and tear it up, let yourself have a 5 minute pity party once in a while and then drop it and go on. Don’t let downers of life impede the rolling in of good times.
9. Enjoy your own company. Treat yourself well.
10. Embrace something that will embrace you back. “Do dogs not drugs.”

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PERIPHERAL NEUROPATHY LITERATURE REVIEW #4

By William B. Donovan MD

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over a hundred medical articles a month written on PN.

I review these references and select good articles that might be most interesting to us neuropathy sufferers. As mentioned in the last newsletter, we will be looking at articles on prevention, evidenced-based treatment, alternative treatment, and novel research.

This is the link to PubMed, the website that will take us to the NLM: www.ncbi.nlm.nih.gov/pubmed/ After you get to PubMed, you will see a line that says “Search PubMed” followed by “for” and a space. Every article in the NLM is given a PMID, an eight digit identification number. Below are PMID numbers of the selected articles. Type the PMID into the space after the “for” and press the ENTER key. You will then see a one paragraph abstract of the article as well as links to related articles.

Here are the latest PMIDs:

- 18940920 A summary of studies done showing decreased pain and increased nerve regeneration in diabetic PN with acetyl-L-carnitine.
- 17914029 A study by CDC of adult diabetics showing PN to be associated with low levels of polyunsaturated fatty acid in the diet.
- 19301937 A study from the University of Schleswig- Holstein comparing oral pregabalin (Lyrica®) with lidocaine 5% medicated plaster found that the efficacy was comparable, but there were 90% fewer adverse events with the local treatment.
- 18796160 An Albert Einstein College of Medicine study of painful diabetic neuropathy showing over twice the response rate for pregabalin (Lyrica®) at 49%, compared with placebo,
- 19387178 A Johns Hopkins study of sciatica showing at least a 50% reduction in pain for the majority of patients at six months following nerve root injection with etanercept (Embrex®).
- 19243312 A University of Leicester review of studies demonstrating prevention and amelioration of diabetic neuropathy with proinsulin C-peptide.
- 19004197 A Guangzhou University study comparing the effectiveness of acupuncture plus acupoint-injection vs. oral carbamazepine (Tegretol®), for occipital neuralgia, with the former being more effective.
- 18636234 A meta-analysis by Wake Forest University demonstrated increased functionality and chronic neuropathic pain relief from the H-Wave device manufactured by Electronic Waveform Lab.

BLOCKING MAY HELP TO PREVENT PAINFUL NERVE CONDITION

By Michael C. Purdy

Scientists have identified the first gene that pulls the plug on ailing nerve cell branches from within the nerve cell, possibly helping to trigger the painful condition known as neuropathy.

The condition is a side effect of some forms of chemotherapy and can also afflict patients with cancer, diabetes, kidney failure, viral infections, neurodegenerative disorders and other ailments.

School of Medicine researchers showed that blocking the dual leucine zipper kinase (DLK) gene inhibits degeneration of ailing nerve cell branches, possibly preventing neuropathy.

“Neuropathy can become so extraordinarily painful that some patients stop taking their chemotherapy, regardless of the consequences in their fight against cancer,” said co-senior author Aaron DiAntonio, M.D., Ph.D., associate professor of developmental biology. “So we’re very excited about the possibilities this gene may offer for reducing the likelihood of developing neuropathy.”

The findings were published this month in *Nature Neuro-science*.

Scientists have known since 1850 that nerve cells have ways to prune branches (also known as axons) that are injured. Although axon pruning is also a normal part of early human development, inappropriate loss of axons in the adult nervous system causes painful sensations that have been compared to burning, freezing or electric shock and are known as neuropathy.

DiAntonio’s lab previously revealed that the fruit fly’s version of DLK helps establish synapses, or junctures where two nerve cells communicate. But they found the gene doesn’t do the same thing in mice.

Curious about DLK’s role in mammals, Bradley Miller, an M.D./Ph.D. student in DiAntonio’s lab, consulted with co-senior author Jeffrey Milbrandt, M.D., Ph.D., the David Clayson Professor of Neurology. Milbrandt studies the role of various proteins in neurodegeneration. With support from the University’s Hope Center for Neurological Disorders, they showed that the long axons of the sciatic nerve in mice with a mutated DLK gene resisted degeneration after the nerve was surgically cut.

In follow-up tests, Miller and Craig Press, an M.D./Ph.D. student in Milbrandt’s lab, took nerve cells in culture and treated their axons with the chemotherapy drug vincristine. Normal axons degenerated rapidly after exposure to the drug, but axons where DLK’s activity had been blocked were protected from degeneration.

“The pain of neuropathy is often a key factor that limits the dose in cancer chemotherapy,” DiAntonio said. “We know when patients are going to start their treatment, so one day it might be possible to start patients on a DLK-blocking drug before chemotherapy and spare them this devastating side effect.”

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GENE THERAPY SHOWS POTENTIAL IN TREATING DIABETIC POLYNEUROPATHY

Boston, MA - Intramuscular injections of vascular endothelial growth factor (VEGF) gene show promise for improving neuropathic symptoms in individuals with diabetic polyneuropathy, a condition most commonly affecting diabetics who have had the disease for many years. These findings were presented in April at the American Academy of Neurology Annual Meeting in Seattle.

Symptoms associated with diabetic polyneuropathy include loss of sensation and pain in the legs and feet, weakness, and imbalance. Due to loss of sensation, the development of ulcerations on the feet often go undetected, potentially resulting in amputation, a procedure 15 times more prevalent in diabetics.

Study participants who received the VEGF gene injection had improvement in sensory symptoms and pain, though not in many other characteristics such as nerve conduction tests. “Most patients had fairly severe neuropathy and the expectation for improvement was therefore not high” said Allan Ropper, MD, executive vice chair of the Department of Neurology at Brigham and Women’s Hospital (BWH).

Preclinical studies using animal models have shown that injecting VEGF into the muscle adjacent to nerve trunks can improve clinical function, blood flow in the nerves, and electrophysiological function.

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DISCOUNTS FOR NCCNA MEMBERS

The following companies or individuals have agreed to give NCCNA a discount to NCCNA members. Give them a call or visit. If you chose to purchase the service or wares of any on this list, pull out your NCCNA Membership Card and claim the discount.

Auburn

The Footpath

825 Lincoln Way
Auburn, CA 95603
(530) 885-2091
www.footpathshoes.com
NCCNA Discount:
10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
Elk Grove, CA
(916) 686-1050
NCCNA Discount:
20% off the regular price shoes.

Fortuna

Strehl’s Family Shoes & Repair

Corner of 12th & Main
1155 Main Street
Fortuna, CA 95540
(707) 725-2610
Marilyn Strehl, C.PED
is a Certified Pedorthic.
NCCNA Discount:
10% off the regular price shoes.

Sacramento

Shoes-n-Feet

4740 Natomas Blvd.
Suite 130,
Sacramento, CA 95835
(916) 419-0040
NCCNA discount:
15% off the regular price

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DISCOUNTS FOR NCCNA MEMBERS

Continued from page 5.

West Sacramento Beverly's Never Just Haircuts and Lilly' Nails

2007 West
Capitol Ave., West
Sacramento, CA
Hair – (916) 372-
5606 Nails – (916)
346-8342
NCCNA discount:
10% off the regular
price

Additional Discounts

Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail info@pnhelp.org. We'll mail an agreement form to the business, and once we have it, we'll get them on this list.

■ BEV ANDERSON SPEAKS IN CONCORD

By Ernette Rivera

Bev Anderson, NCCNA President spoke on “The Brain, the Spinal Cord, and The Peripheral Nervous System.” Bev started out by stating, “Not long ago, I started describing neuropathy (the most common disease you’ve never heard of) a new way that cuts straight to the chase and is a very simple way to introduce it to people who have never heard of it. I’d like to teach it to you so you can easily tell people who ask, ‘What is neuropathy?’”

And indeed she did just that as she explained how the brain and spinal cord are the Central Nervous System and all the rest of the nerves in the body are peripheral nerves. Any disease or disorder in the peripheral nerves is called neuropathy (neuritis or syndrome are other terms for neuropathy).

With handouts of the spinal nerve function and the book ‘*Coping with Peripheral Neuropathy – How to Handle Stress, Disability, Anxiety, Fatigue, Depression, Pain and Relationships*’ by Scott I. Berman, MD, CIDP (Chronic Inflammatory Demyelinating Polyneuropathy (poly meaning more than one neuropathy), she relates Dr. Berman’s explanation.

The central nervous system comprises the brain and the spinal cord. **Peripheral Nerves** coming off the central nervous system consist of sensory nerves, motor nerves and autonomic nerves. **Sensory Nerves** carry position sense and vibration, pain and temperature. These are large fibers (carry position sense) and small fibers (pain and temperature), which can be myelinated (coated with a special sheath) or unmyelinated. **Motor Nerves** control muscle movement. **Autonomic Nerves** control involuntary processes such as breathing, heartbeat, and blood pressure.

By convention, peripheral neuropathy consists of sensory or mixed motor sensory neuropathies, while nerve-muscle disease is termed “neuromuscular.” There is a fair bit of overlap.

A list of some causes are:

Compressive/traumatic – Carpel tunnel syndrome (wrist) and Tarsal tunnel syndrome (ankle)

Connective Tissue Disease - Rheumatoid arthritis, Polyarteritis nodosa, Systemic lupus erythematosus, Churg-Strause vasculitis, Cryoglobulinemia, Sjogren’s syndrome

Drug Induced – Long list of drugs & prescriptions

Endocrine – Diabetes, hypothyroidism

Hereditary – Charcot-Marie-Tooth disease. (Bev has HN and is a member of the Hereditary Neuropathy Association. Another member of our group stated they may have HN, also.)

Infectious – HIV, Lyme disease

Inflammatory – Guillan-Barre, CIDP, or MMN (multifocal motor neuropathy)

Nutritional – Alcoholism, B-12 deficiency, folic acid deficiency, thiamine deficiency and overdoses of B6

Paraneoplastic – Secondary to lung cancer, lymphoma, myeloma, others

Toxic – Lead, arsenic, mercury, gold, thallium, carbon monoxide, glue sniffing

As we continually state in our group discussions, one must carefully consider the skills and personality of the neurologist you choose. **Dismiss any doctor who tells you that there is nothing that can be done for you.** He should tell you that he can’t think of anything else to do at the present, but he should never take away all hope by giving up on you. Ask to be referred to other specialists to see what else might help. It is important for you to get treatment for the disabilities caused by the illness such as depression, fatigue, weakness, and pain. **AND** – dismiss as a quack anyone who promises a complete cure or 100% success or other similar unrealistic claims. **REAL** treatments have real failure rates!

Below are some tips that Bev shared with us:

1. **Keep learning** – Book by Scott I. Berman, per above and the Mims Cushing’s and Norman Latov, MD book “You Can Cope with Peripheral Neuropathy.” Also see the website: www.ittakesnerve.org and ours www.pnhelp.org
2. **Come regularly to a support group** – Share info with members and be ready to learn from them and the speakers!
3. **Volunteer to help with the group** – All groups welcome and need help so the leaders aren’t doing it all.

Bev Anderson Speaks in Concord - continued from page 6

Bev stated in order to help ourselves, we need to get all the information on neuropathy that we can. One of the best ways to help ourselves is to help others. We actually learn more in this process as it keeps us actively involved in life which benefits us and others. (A good example is - information from our speakers and sharing experiences with our members via our monthly support group meetings.)

It is estimated that there are 36,458,000 people living in California. Using the formula Bev described during the meeting, she estimates that there are over 2 million people that have neuropathy. That is approximately 76 out of every 1000 people.

In closing, Bev asked, "Are you willing to help let these people know about neuropathy? The first thing to do is to join NCCNA, if you are not already a member. Get others to join! In joining, you are saying you care about yourself and others, and they hear about neuropathy and you get more information."

Thanks, Bev, for a great presentation. Your knowledge increases with each year and we are lucky to have you come and speak to us, hopefully a yearly event. As usual, I look forward to learning more about neuropathy and hopefully we can all find something that will "stay" our neuropathies from progressing.

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Gene Therapy Shows Potential in Treating Diabetic Polyneuropathy - Continued from page 5

Thirty nine patients were randomly chosen to receive three sets of intramuscular injections of plasmid VEGF in one leg while 11 patients received a placebo in one leg. The injections were given at eight standardized sites adjacent to the sciatic, tibial, and peroneal nerves. Six months after treatment, participants receiving the VEGF injection had greater improvement in symptoms in the injected leg than those receiving the placebo.

In this study, the investigators used a form of the gene that is active without packaging it in a virus, offering a major advantage in safety.

"The study shows that this form of gene transfer therapy can be performed relatively safely but further investigation using a larger study group is needed before it can be introduced as a mainstream therapy," said Dr. Ropper, noting that this study was limited by its small size and rigid participation criteria.

*Used by permission of Brigham and Women's Hospital
Brigham and Women's Hospital (BWH) is a 777-bed nonprofit teaching affiliate of Harvard Medical School and a founding member of Partners HealthCare, an integrated health care delivery network. Please visit www.brighamandwomens.org*

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Be Aware & Be Heard - continued from page 1

If you do not have access to the website, just call or write, and we will send you the meeting information or the policies up for comment (or both). If you want to receive this information ongoing, let us know and we'll make sure it happens. If you want an e-mail notice when things are posted, we will accommodate that as well.

The NCCNA exists primarily to provide support to our members through our groups.

The board of directors values our members and needs feedback from both individuals and groups, both active members and leaders. So please check out our information and respond.

Another way to participate is to come to our strategic planning meeting on September 26. See our president's report for more on that.

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CHECK LOCAL RESOURCES

Sometimes local agencies have classes or activities helpful to people with neuropathy. Watch listings in the newspapers, posters in local areas, or contact agencies you think might be providing something of interest. For example, Cure Arthritis Now (www.CureArthritisNow.org) provided Free Pole Walking Clinics at four locations in the Sacramento area during May, 2009. Their poster had coupons to tear off that had the information and phone number. Your local hospital or library may know of these or can give you a referral to a service that lists such activities.



**The Northern California Chapter
of The Neuropathy Association**

A California public benefit, nonprofit,
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Third Annual Neuropathy Action Awareness Day

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new Explanation of Benefits fully and never, ever, let your policy lapse. Elsewhere in this newsletter is a recap of the opening presentation by Mims Cushing, author of **You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life.**

Along with the additional doctors and others who spoke, California State Senator Leland Yee and Assemblywoman Mary Hayashi took brief breaks from their budget meetings to address those attending. Assemblywoman Hayashi has worked extensively with NAF on issues of concern to neuropathy patients.



Claudia Foutz presents Martha Chandley with NAF's "You Are Our Hero" award.

Martha Chandley, longtime leader of the NCCNA's group in Davis and a passionate advocate for those with neuropathy, received the "You Are Our Hero" award for all her extensive work to educate and assist so many.

The NCCNA videoed every speaker, and we hope to be able to provide DVDs to every support group. NAF also recorded some of the presentations. We don't know what their distribution plans are.



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Hope through caring and education

Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year (due each January)
(Prorated for new members at \$2.50
per each month left in the year)
All contributions are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and, occasionally, small grants.

This newsletter is designed for educational and informational purposes only. The information contained herein is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. The Northern California Chapter of the Neuropathy Association (NCCNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.